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# **A participatory approach to developing an HIV Nursing Research Strategy**

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## **Introduction**

As an illness that has changed dramatically over the past three decades, HIV has kept healthcare professionals working in the field engaged and challenged. From the caution and concerns of an emerging infection in the early 1980s providing palliative and end of life care, through the emergence of successful drug therapies and finally to the identification as a long term health condition, health professionals caring for people with HIV have had to adapt their knowledge and skills to meet their client group. Nurses have played an important role in the adaptation of care priorities and knowledge acquisition through the delivery of evidence based clinical practice and research development when the evidence did not exist. This paper outlines how the National HIV Nurses Association (NHIVNA) in the United Kingdom explored the research priorities for nurses in the changing environment of HIV nursing care and management in order to develop a nursing research strategy that is progressive.

## **Background**

Since its origins in 1998, NHIVNA has committed to promoting excellence in the care of those living with and affected by HIV. Fundamental to this is a commitment to promote high quality research and knowledge creation that can inform evidence-based practice and improve the lives of those living with HIV. Thus far, promotion of research has been realised in relation to a series of separate studies using various methodologies that have individually contributed to the existing knowledge base. For example, a national nurse-led clinical audit of the standards for psychological support for adults living with HIV [1] helped to identify current level of provision and identified gaps in clinical services with recommendations for future practice. The introduction of 'Treatment as Prevention' encouraged an evaluation of nurses' knowledge, attitudes and practices [2] and a metasynthesis of the provision and management of HIV testing from a Health Professional's perspective was completed in 2014 [3], introducing the systematic review process as a method of investigation to HIV nurses. In 2016 NHIVNA undertook a research study that explored shared decision-making in HIV nursing care [4,5], enabling HIV nurses to review their current practices, challenge their assumptions and consider ways in which they could encourage this relationship further with their clients. Another key activity that supports and promotes the research agenda is the annual conference which creates opportunities for the NHIVNA membership and their associates to present their own studies as well as facilitating networking and sharing of ideas in new challenges and developments. A key aspect of the conference is its contribution to increasing research capacity and capability within the HIV nursing workforce, for example by attendance scholarships, achievement awards and active encouragement for healthcare students to present work and engage with the HIV agenda.

In 2016, the NHIVNA executive committee determined to adopt a more strategic approach to increasing the amount of high quality HIV nursing research, evaluation and audit, and to support research capacity and capability development within the NHIVNA membership.

This article details how we developed the strategy document.

## **Methods**

We used a two part consultation process. The first part was a consensus workshop to outline the scope of the strategy and identify research priority areas. Part two was a survey of the NHIVNA membership.

### **Consensus workshop**

Stage one involved a one day workshop convened with a purposive sample of NHIVNA members (n = 14) Participants were selected by reputation on the basis of their research expertise and experience in HIV nursing research and included both clinical (n=10) and academic (n=4). Three participants were members of the NHIVNA executive committee. The workshop took place in May 2017. We structured the workshop using a modified form of Nominal Group Technique. This is a consensus methodology, originally developed in the 1950's and widely used since for eliciting opinions from a group of skilled and experienced individuals, aggregating judgements and developing consensus between them [6,7]. It does this through a structured face-to-face interaction and uses an orderly procedure involving a series of individual and group processes to obtain and manage qualitative information. These processes are designed to capture the contributions of all individuals and to stimulate significant idea generation through discussion and debates [8]. The process involved three rounds of idea generation and consensus building.

Round 1: Participants undertook a time limited exercise where they were asked to list individually, using separate post-it notes, their own areas of research interest and expertise and their thoughts and ideas in response to the nominal question 'what direction does HIV nursing research needs to be moving in?' Their responses were then shared with the group in a round-robin fashion, each person in turn presenting the most important idea on his or her list until all lists were exhausted. These were then organised by grouping them under a set of category headings.

Round 2: Small group discussions were then undertaken. This involved the creation of three smaller groups of four to five people, with each group discussing and collectively reflecting on the outputs from the previous exercise to identify the current HIV nursing research priorities. Each group was asked to employ a discursive ranking process to agree their three priority areas.

Round 3: The final round was a whole group activity. Each small group presented and justified the priorities areas they had identified. These were then considered by the whole group and through a process of discussion, clarification and evaluation, resulted in a consensus agreement of three overarching themes that effectively captured the previous deliberations.

### **Membership survey**

Following the workshop, a survey was developed by the research team to canvass the entire NHIVNA membership's opinions on the outcomes of the workshop. It captured data on the following areas: individual levels of research experience and engagement, views on the appropriateness of the three proposed research themes and the appetite to contribute to a national HIV nursing research agenda. The questionnaire was constructed using surveymonkey™ and was comprised of 17 open and closed questions. A link to the survey was sent to NHIVNA members via email in August 2017. A follow up email was sent 3 weeks later.

## **Results**

## **Outcomes of the workshop**

The nominal question 'what direction does HIV nursing research needs to be moving in?' generated sixty responses from the fourteen participants. These were organised under thirteen broad category headings which aimed to group together those that were comparable in one or more aspect. Some categories were wide ranging, for example nursing education and development and models of HIV care. Some focussed on specific populations, for example growing older with HIV and others focused on specific social or clinical issues of concern, for example stigma, testing and diagnosis, Pre-exposure prophylaxis (PREP). The number of issues under each heading ranged from 2-15. The following two examples illustrate the categorisation process and the breadth of topics identified:

- **Stigma**
  - Relations between HIV, stigma, stress and cardiovascular disease
  - HIV stigma/health related stigma
  - Stigma reducing interventions
  - Health care professional stigma - lack of updated knowledge about HIV
- **Growing older with HIV**
  - Older women's experience of living with HIV
  - HIV and elderly care
  - Care homes for dementia and people living with HIV
  - Health care professionals dealing with ageing HIV population and co-morbidities
  - Clinical experience of the over 50's
  - HIV patients' perspectives on the care they need as they age

The round two deliberations indicated a considerable degree of consensus in terms of what were the priority areas. Differences in terms of priority rankings and the specific issues proposed to be covered within those priority areas reflected the range of clinical and research interests of participants. To capture this variability, we organised the output from all the groups under three preliminary categories. In round three, these categories were refined through discussion which resulted in consensus agreement of the three following research themes.

1. Health care delivery
2. Patient experience
3. Developing a workforce

## **Survey results**

A total of 29 respondents completed the survey. This represents 8.7% of the total NHIVNA membership (251 registered members in 2017).

89% (n=23) of respondents were female, 11% (n=6) were male. The majority (41%, n=12) were aged between 45 and 54.

Respondents were asked to identify their area(s) of HIV nursing. The majority of respondents 79% identified as clinical (n=23), followed by 38% research (n=11), 34% managerial (n=10) and 31% education (n=9). Over half (55% n=16) self-identified as practising across more than one area.

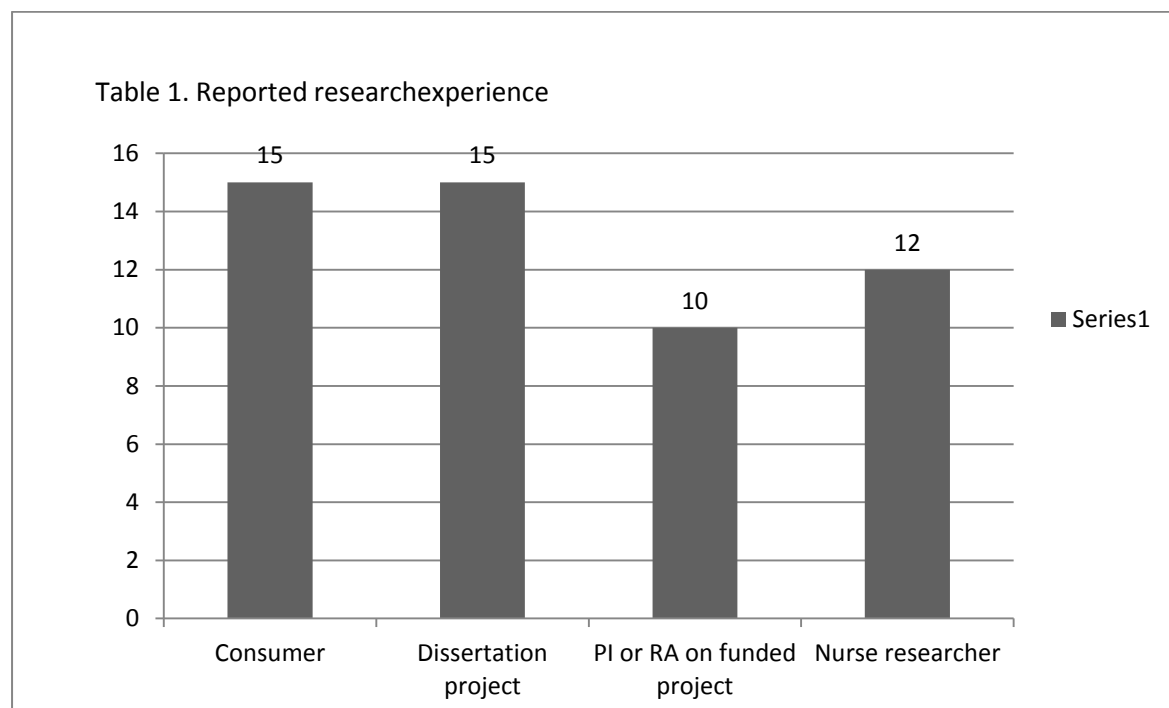
## **Training and experience**

In terms of research qualifications, 41% (n = 12) were qualified to masters or doctoral level.

12 had completed Good Clinical Practice (GCP) training and 5 had received training on specific research techniques.

Figure 1 demonstrates the range of research experience.

*Figure1: Research experience.*



### Areas of research interest

In a free text section, respondents were asked to identify their areas of research interest. Their responses indicated a wide range of interests. These were categorised into 4 groups and are presented in table 1. Several respondents also indicated interest in aspects of research design and delivery including methodologies and research governance.

*Table 1: Current areas of research interest*

Patient experience	Clinical Practice	Health care delivery	Education
Health beliefs	sexual health	HIV models of care	HIV nurse education
Older people care	HIV testing	Managing a long-term condition	Knowledge of staff who work in areas other than HIV.
Psychological issues/mental health	HIV treatment,	Service improvement and MDT collaboration	
Physical and mental health of MSM stigma	Hepatitis C,	Project monitoring and evaluation in the international health sector	
women experience of growing older with HIV	Hepatitis B	Quality improvement/patient safety	

patient and clinical experiences	Health promotion	Access and uptake of services among black Africans living with HIV	
health seeking behaviour	Treatment adherence		
HIV transmission, and recreational drug use among MSM.	engaging and supporting complex patients,		
	clinical outcomes following nurse intervention		
	HIV Pharmacology		

### Views on a national HIV nursing research strategy

100 % of those who responded to the question 'Do you think development of a national research strategy for HIV nurses would be useful?' said yes (n=28). One person did not respond.

23/29 provided freetext comments to the question 'How would you see a research strategy benefitting you and your work?' Collectively they suggested that it would help to focus research activities, enhancing and sharing practice, identifying research collaborators, align research activities with health priorities, evidence the contribution of nursing to HIV care provision, raise the profile of nurse researchers in HIV and most importantly improve patient care.

The following responses indicate the main areas of perceived benefit.

*'I think this is a very exciting development. A research strategy can help us to develop strong research networks and use these networks to a) undertake high quality research projects that addresses current priorities and can make a significant contribution to HIV treatment and care and b) increase HIV research nursing capacity and capability.'*

(female respondent, aged 55-64 working in research)

*'to embed nurse-led research on the agenda for HIV nurses'*

(female respondent, aged 35-44, working in clinical/education)

*'nurses are in unique position to liaise between disciplines and with patient to undertake research. Having a national strategy would be great to develop nurses' potential to become researchers'*

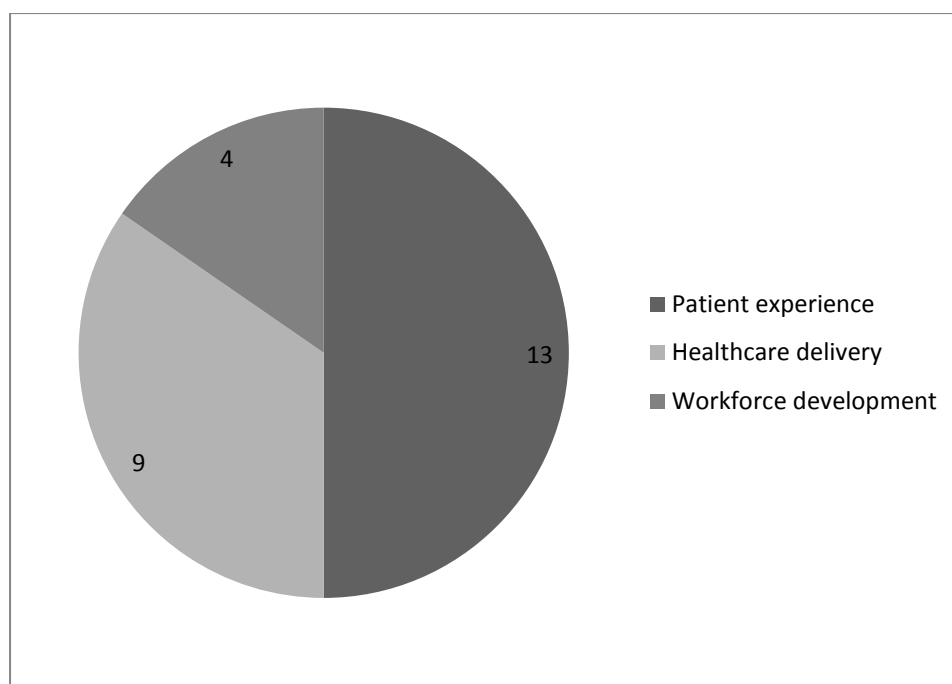
(female respondent, aged 45 – 54, working in clinical/education/research)

### Views on the three research themes

Respondents were asked to comment on the research themes identified at the workshop. Of those who responded (n=23) most were in agreement that these themes were useful, and effectively captured research priorities. 54% (n=15) reported that they were currently involved in research that would sit under these themes. 50% (n=13) expressed a preference for being involved in a specific theme (see fig 2). In terms of the type of

involvement, the majority (63%, n=17) wanted to take part in conducting a study, 59% (n=15) wanted to support someone undertaking a study, 18% (n=5) wanted to support other to source funding and 7% (n=2) wanted to complete a research dissertation.

*Figure 2: Proportion interested to be involved in each theme.*



## Discussion and Conclusion

The development of a strategy assists organisations to identify their priorities and provide a structured plan for future endeavours. It helps to create a shared focus and responsibility for all those involved. Importantly to gain that shared focus and vision, all stakeholders should be given the opportunity to participate and contribute to the strategy's objectives. The method used by NHIVNA to create this strategy was true to this philosophy. NHIVNA members were included at each stage of the development process; firstly as experienced clinicians and academics and secondly as the whole membership of the association.

The consultation workshop provided a vibrant and engaged discussion and debate of the priorities for HIV nurses and their clients. The use of nominal group technique as a methodology was effective in identifying topics and enabling a group consensus leading to the formulation of the three themes presented. This was a successful approach, which helped to focus what can appear to be disparate topics into a more structured collective. Generating the topics and organising them into themes was done by the same people and there was no external verification of the thematic structure. This is consistent with a consensus methodology and involving all 14 participants in this process ensured that it was robust.

The three themes identified at the consultation workshop were considered pertinent to the requirements of people living with HIV today and this was supported through the membership survey. Perhaps, unsurprisingly, the health, wellbeing and quality of life of people living with HIV attracted the highest responses and it can be argued that this is reflective of the care landscape that the majority of HIV nurses are working in.

The survey demonstrated that a number of NHIVNA members are already involved in a wide range of research projects and activities and that there is substantial research experience and expertise within the workforce. The survey response rate was low and it

is highly likely that the survey would have been completed by those who are research active. As the survey was distributed to all the membership, some of the respondents may have participated in the workshop. Over half of the respondents indicated a commitment to developing capacity in the HIV nursing workforce, by supporting others to undertake projects and to secure funding. This is extremely positive. Developing an implementation plan that enables us to capitalise on this level of commitment and enthusiasm for the benefit of the HIV nursing workforce and those receiving our care and support will be a vital component of the strategic research development activities.

## Conclusion

This two stage consultation process has provided a firm foundation for developing a NHIVNA Research Strategy. A document has been developed and published in 2018 which provides a strategic vision for HIV nursing research for the next five years and details how it can be operationalised [9].

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